

### What is it?

Sturge-Weber syndrome is a neurological and vascular condition caused by a genetic mutation. Mutation occurs after conception and is not an inherited trait. Three types of SWS have been identified by varying degrees of involvement.

The syndrome is characterized by a port-wine stain birthmark on the forehead and upper eyelid of one side of the face. The birthmark can vary in color from light pink to deep purple and is caused by an overabundance of capillaries around the trigeminal nerve just beneath the surface of the face.

Sturge-Weber syndrome is also characterized by neurological concerns caused by the development of abnormal blood vessels on the surface of the brain as well as the loss of nerve cells. Calcifications can also occur on the underlying tissue in the cerebral cortex of the brain; on the same side of the brain as the birthmark. Neurological symptoms most notably include seizures that begin in infancy and may worsen with age. The seizure activity usually happens on the side of the body opposite the birthmark. Those who develop a seizure history in infancy usually have a poorer prognosis. Children with SWS can also be diagnosed with glaucoma because of the abnormal blood vessels in their eyes. Glaucoma has 2 peak periods; one in infancy and one in later young adulthood.



*“Based on seizure history and brain involvement, in a physical sense, Sturge-Weber syndrome can be disabling. In an emotional sense, it can be challenging, especially for those with a facial port wine stain.”*  
*-Sturge-Weber Foundation*

### What are other medical concerns?

- Hemiparesis (opposite side of port wine stain)
- Internal organ irregularities
- Delayed mental and physical development
- Mood and behavior problems
- Vision field cuts
- Migraines
- Headaches
- Hormonal issues

## Suggested school accommodations

- Early intervention assessment for young children
- IEP or 504 plan, updated as appropriate
- PT/OT/SLP/Vision specialist consult
- Emotional support
- IEP or 504 plan
- Seizure training for staff
- Preferential seating
- Copies of notes, whiteboard, presentations in proper font size
- Possible assistive technology
- Extended time for testing
- Rest period if needed
- Accommodations if student is having surgery
- Revisiting work if student has seizures

## **SHNIC school nurses information:**

### **Specific health issues for individual health care plans**

- Diagnosis including type of seizure, description of, typical length, characteristics, triggers, warning signs, how often seizures occur, and student's behavior following a seizure
- Current medication list for home and school
- Orders for emergency medications, when to administer, dose, route
- Note if seizures are controlled
- Seizure action plan, when to call 911
- Documentation/log of seizures
- Orders for hidden device like a vagus nerve stimulator, how to use/manage
- Bleeding precautions in event injury occurs at area of birthmark
- Plan for monitoring headaches and neurological changes
- Orders for fluid intake goals for student to stay hydrated
- Provide rest area if needed



**THE STURGE-WEBER FOUNDATION**  
The stronger the wind, the tougher the trees



## Resources & Manuals

**Sturge Weber Foundation**  
<http://www.sturge-weber.org/>

**National Institute of Neurological Disorders and Stroke**  
[http://www.ninds.nih.gov/disorders/sturge\\_weber/sturge\\_weber.htm](http://www.ninds.nih.gov/disorders/sturge_weber/sturge_weber.htm)

**SW Foundation Patient Resources**  
(includes school nurse brochure, info kit for classroom & a child's guide to SW)  
<http://www.sturge-weber.org/library/patient-resources.html>

**Vascular Birthmark Foundation**  
<http://birthmark.org/>